

General

Title

Palliative and end-of-life care: percentage of patients with chart documentation of preferences for life sustaining treatments.

Source(s)

National Quality Forum (NQF). Palliative and end-of-life care 2015-2016: technical report. Washington (DC): National Quality Forum (NQF); 2016 Dec 23. 209 p.

The Carolinas Center for Medical Excellence (CCME). Specifications for recommended quality measures. Cary (NC): The Carolinas Center for Medical Excellence (CCME); 8 p.

Measure Domain

Primary Measure Domain

Clinical Quality Measures: Process

Secondary Measure Domain

Does not apply to this measure

Brief Abstract

Description

This measure assess the percentage of patients with chart documentation of preferences for life sustaining treatments.

Rationale

This measure addresses patient autonomy for patients with high severity of illness and risk of death, including seriously and incurably ill patients enrolled in hospice or hospital-based palliative care. The National Priorities Partnership has identified palliative and end-of-life care as one of its national priorities. A goal of this priority is to ensure that all patients with life-limiting illness have the right to express preferences that guide use of invasive or life-sustaining forms of treatment. The affected

populations are large; in 2009, 1.56 million people with life-limiting illness received hospice care ("NHPCO facts and figures," 2010). In 2008, 58.5% of United States (U.S.) hospitals with 50 or more beds had some form of palliative care service, and national trends show steady expansion of these services ("Palliative care programs," 2010).

Patients and family caregivers rate control over treatment decisions as a high priority when living with serious and life-limiting illnesses (Singer, Martin, & Kelner, 1999). From a recent systematic review of clinical trials, moderate evidence supports multicomponent interventions to increase advance directives, and "care planning through engaging values, involving skilled facilitators, and focusing on key decision makers." These studies found improved outcomes of patient-physician communication, improved satisfaction with care, and increased hospice enrollment (Lorenz et al., 2008). The more recently published Coping with Cancer Study, a prospective observational study of over 300 patients with advanced cancer, found that communication of patient treatment preferences was associated with use of treatments honoring those preferences and with lesser use of aggressive, high-cost treatments (Wright et al., 2010; Wright et al., 2008).

Evidence for Rationale

Lorenz KA, Lynn J, Dy SM, Shugarman LR, Wilkinson A, Mularski RA, Morton SC, Hughes RG, Hilton LK, Maglione M, Rhodes SL, Rolon C, Sun VC, Shekelle PG. Evidence for improving palliative care at the end of life: a systematic review. *Ann Intern Med.* 2008 Jan 15;148(2):147-59. [152 references] [PubMed](#)

NHPCO facts and figures: hospice care in America. [internet]. Alexandria (VA): National Hospice and Palliative Care Organization; 2010 Sep.

Palliative care programs continue rapid growth in U.S. hospitals becoming standard practice throughout the country. [internet]. New York (NY): Center to Advance Palliative Care; 2010 Apr 6.

Singer PA, Martin DK, Kelner M. Quality end-of-life care: patients' perspectives. *JAMA.* 1999 Jan 13;281(2):163-8. [PubMed](#)

University of North Carolina - Chapel Hill. National Quality Forum (NQF) measure submission and evaluation worksheet 5.0: Hospice and palliative care - treatment preferences. 16 p.

Wright AA, Mack JW, Kritek PA, Balboni TA, Massaro AF, Matulonis UA, Block SD, Prigerson HG. Influence of patients' preferences and treatment site on cancer patients' end-of-life care. *Cancer.* 2010 Oct 1;116(19):4656-63. [PubMed](#)

Wright AA, Zhang B, Ray A, Mack JW, Trice E, Balboni T, Mitchell SL, Jackson VA, Block SD, Maciejewski PK, Prigerson HG. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA.* 2008 Oct 8;300(14):1665-73. [PubMed](#)

Primary Health Components

Palliative care; end-of-life care; life sustaining treatments; patient preferences

Denominator Description

Seriously ill patients enrolled in hospice OR receiving specialty palliative care in an acute hospital setting (see the related "Denominator Inclusions/Exclusions" field)

Numerator Description

Patients whose medical record includes documentation of life sustaining preferences (see the related "Numerator Inclusions/Exclusions" field)

Evidence Supporting the Measure

Type of Evidence Supporting the Criterion of Quality for the Measure

A clinical practice guideline or other peer-reviewed synthesis of the clinical research evidence

A systematic review of the clinical research literature (e.g., Cochrane Review)

One or more research studies published in a National Library of Medicine (NLM) indexed, peer-reviewed journal

Additional Information Supporting Need for the Measure

Seriously ill and dying patients who are given the opportunity to express life-sustaining treatment preferences are more likely to receive care consistent with their values, and patient and family satisfaction outcomes improve. Patients and physicians alike hesitate to initiate discussions, while acknowledging their value and desirability. Use of the Treatment Preferences quality measure will improve attention to this important practice, in order to enhance patient autonomy, facilitate patient centered decision-making, and communicate patient preferences via documentation to other treating providers.

Poor communication about patient preferences has been identified as a major quality concern in palliative and end-of-life care since an early, comprehensive Institute of Medicine report (Field & Cassel, 1997). The SUPPORT Study found marked discrepancies between patient report of treatment preferences and provider awareness of or use of these preferences to guide treatment ("A controlled trial," 1995). Patients and families prioritize communication with providers and control over treatment choices when faced with serious or life-threatening illness (Steinhauser et al., 2001). However, physicians and other providers fail to open the door to these discussions at critical time points in illness progression (Gysels, Richardson, & Higginson, 2004). A recent systematic review of communication research found a consistent discrepancy between the quality and content of communication providers believed they provided, and the quality and content of communication experienced by seriously ill patients and their families (Hancock et al., 2007).

In advanced incurable illness, treatment options range from life-sustaining and disease modifying interventions to control of acute exacerbations to hospice care. African Americans with advanced cancer less often access treatment through clinical trials, palliative care for pain management, or hospice (Smith, Earle, & McCarthy, 2009; Cintron & Morrison, 2006). They less often prepare advance directives, including Health Care Powers of Attorney that can facilitate family advocacy during illness (Hanson & Rodgman, 1996; Murphy et al., 1996; Morrison et al., 1998; Tilden et al., 2004; Kiely et al., 2001; Hopp & Duffy, 2000). If these choices are fully informed expressions of values, they should be supported. However, African Americans desire more information on treatment options and are less likely to have discussions with their physicians, indicating that communication and information access serve as barriers to optimal care (McKinley et al., 1996; Borum, Lynn, & Zhong, 2000; Haas et al., 1993; Born et al., 2004).

Evidence for Additional Information Supporting Need for the Measure

A controlled trial to improve care for seriously ill hospitalized patients. The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). The SUPPORT Principal Investigators. JAMA. 1995 Nov 22-29;274(20):1591-8. [PubMed](#)

Born W, Greiner KA, Sylvia E, Butler J, Ahluwalia JS. Knowledge, attitudes, and beliefs about end-of-life care among inner-city African Americans and Latinos. *J Palliat Med*. 2004 Apr;7(2):247-56. [PubMed](#)

Borum ML, Lynn J, Zhong Z. The effects of patient race on outcomes in seriously ill patients in SUPPORT: an overview of economic impact, medical intervention, and end-of-life decisions. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. *J Am Geriatr Soc*. 2000 May;48(5 Suppl):S194-8. [42 references] [PubMed](#)

Cintron A, Morrison RS. Pain and ethnicity in the United States: A systematic review. *J Palliat Med*. 2006 Dec;9(6):1454-73. [50 references] [PubMed](#)

Field MJ, Cassel CK, editor(s). Approaching death: improving care at the end of life. Washington (DC): National Academy Press (Institute of Medicine); 1997. 437 p.

Gysels M, Richardson A, Higginson IJ. Communication training for health professionals who care for patients with cancer: a systematic review of effectiveness. *Support Care Cancer*. 2004 Oct;12(10):692-700. [31 references] [PubMed](#)

Haas JS, Weissman JS, Cleary PD, Goldberg J, Gatsonis C, Seage GR 3rd, Fowler FJ Jr, Massagli MP, Makadon HJ, Epstein AM. Discussion of preferences for life-sustaining care by persons with AIDS. Predictors of failure in patient-physician communication. *Arch Intern Med*. 1993 May 24;153(10):1241-8. [PubMed](#)

Hancock K, Clayton JM, Parker SM, Walder S, Butow PN, Carrick S, Currow D, Ghera D, Glare P, Hagerly R, Tattersall MH. Discrepant perceptions about end-of-life communication: a systematic review. *J Pain Symptom Manage*. 2007 Aug;34(2):190-200. [60 references] [PubMed](#)

Hanson LC, Rodgman E. The use of living wills at the end of life. A national study. *Arch Intern Med*. 1996 May 13;156(9):1018-22. [PubMed](#)

Hopp FP, Duffy SA. Racial variations in end-of-life care. *J Am Geriatr Soc*. 2000 Jun;48(6):658-63. [PubMed](#)

Kiely DK, Mitchell SL, Marlow A, Murphy KM, Morris JN. Racial and state differences in the designation of advance directives in nursing home residents. *J Am Geriatr Soc*. 2001 Oct;49(10):1346-52. [PubMed](#)

McKinley ED, Garrett JM, Evans AT, Danis M. Differences in end-of-life decision making among black and white ambulatory cancer patients. *J Gen Intern Med*. 1996 Nov;11(11):651-6. [PubMed](#)

Morrison RS, Zayas LH, Mulvihill M, Baskin SA, Meier DE. Barriers to completion of healthcare proxy forms: a qualitative analysis of ethnic differences. *J Clin Ethics*. 1998 Summer;9(2):118-26. [PubMed](#)

Murphy ST, Palmer JM, Azen S, Frank G, Michel V, Blackhall LJ. Ethnicity and advance care directives. *J Law Med Ethics*. 1996 Summer;24(2):108-17. [PubMed](#)

Smith AK, Earle CC, McCarthy EP. Racial and ethnic differences in end-of-life care in fee-for-service Medicare beneficiaries with advanced cancer. *J Am Geriatr Soc*. 2009 Jan;57(1):153-8. [PubMed](#)

Steinhauser KE, Christakis NA, Clipp EC, McNeilly M, Grambow S, Parker J, Tulsky JA. Preparing for the end of life: preferences of patients, families, physicians, and other care providers. *J Pain Symptom Manage*. 2001 Sep;22(3):727-37. [PubMed](#)

Extent of Measure Testing

Reliability Testing

Data/Sample. Two research nurse abstractors independently recorded quality measures data on a random subset of 20 seriously ill patients. Abstractors used the pre-defined operational definitions and a structured chart abstraction tool to record numerator and denominator data separately. Patients were a subsample of 460 seriously ill patients without specialty palliative care admitted to an acute care hospital for at least 1 day to four inpatient services. Records eligible for sampling included all seriously ill adult patients admitted to medical and surgical intensive care, medically complex patients aged 65 and older admitted to an acute care of the elderly unit, and medical oncology patients with Stage IV carcinoma.

Analytic Method. Inter-rater reliability between the two abstractors was assessed using kappa statistics.

Testing Results. The nurse abstractors achieved perfect ($Kappa=1.0$) inter-rater reliability for this measure.

Validity Testing

Data/Sample. Hospice: The total patient sample size was 126. Fourteen hospices, located in seven different states, representing both free-standing and hospital based providers were recruited to participate. Each hospice was asked to contribute data from nine patient records to the study. Nine hospices were asked to collect data on their most recent nine discharges; five hospices were asked to collect data on their most recent nine admissions.

Palliative Care: The total patient sample size was 562. Chart abstractions were completed for 102 consecutive seriously ill patients with specialty palliative care consultation, and a random sample of 460 seriously ill patients without specialty palliative care admitted to an acute care hospital for at least 1 day to four inpatient services with high proportions of seriously ill patients. Records eligible for sampling included all patients admitted to medical and surgical intensive care, medically complex patients aged 65 and older admitted to a geriatric evaluation unit, and medical oncology patients with Stage IV carcinoma. Because palliative care domains become even more relevant closer to death, patients dying in hospital were oversampled to ensure a final ratio of 1 decedent to 1 live discharge. Consistent with oversampling of decedent records, 55% of these patients died in hospital. The age of the patients ranged from 16 to 99 years, with the mean age 61. Patients were predominantly Caucasian (65%), with smaller subgroups who were African American (24%) and Hispanic/Latino (4%). The most common life-limiting diagnoses were infections (37%), cancer (34%), pulmonary (29%), and neurologic diseases (21%).

Analytic Method. Hospice sample: Face validity was tested using formal expert panel review. The PEACE project team convened a 14-member technical expert panel (TEP) of nationally recognized experts with extensive experience in the following areas: medical or nursing expertise in hospice and palliative care, methods and instrumentation, and quality improvement. Using criteria provided by the Carolinas Center for Medical Excellence (CCME) study team, TEP members rated each potential quality measure from 1 (low) to 5 (high) on four criteria: importance, scientific soundness, feasibility and usability. The rating criteria mirrored those used by the National Quality Forum and the Centers for Medicare & Medicaid Services (CMS) Measures Management System. To identify the measures with the most favorable ratings, a summary measure was created. For each quality measure, the average TEP rating was calculated for each criterion and then an overall average measure rating (AMR) was tabulated, weighting each the criteria equally.

Palliative Care sample: Face validity of PEACE quality measures for hospital-based specialty palliative care was addressed using stakeholder review and feedback. Investigators prepared data reports in a summary format with detailed operational definitions, and led a 1-hour discussion with nursing and physician leaders from each service group – medical intensive care unit (MICU), surgical intensive care unit (SICU), acute care for the elderly (geriatrics), oncology, and palliative care. The discussion included feedback of quality measure data, response to questions and critiques, and eliciting stakeholder feedback about the validity and actionability of this data for the care of their patients. Stakeholders were specifically asked to comment on the accuracy of the data as a reflection of current care practices, and their highest priority area for future quality improvement.

Construct validity was tested by comparing the PEACE quality measures for patients seen by specialty interdisciplinary palliative care consultants to those not receiving specialty palliative care services.

Testing Results. Hospice sample: Completed ratings were received from 13 of the 14 TEP members. The 75th percentile cut-point translated into an AMR=3.73 (on a scale of 1 to 5 where 5 is highest). This process resulted in the identification of 23 measures with the highest TEP ratings for importance, scientific soundness, feasibility and usability. Medical record documentation of life-sustaining preferences had an overall rating of 4.04.

Palliative Care sample: Face Validity: Stakeholder discussions provided broad endorsement of face validity, with some considerations for specific patient populations. Medical oncologists endorsed the face validity of these quality measures, but favored quality measures endorsed by oncology professional organizations.

Construct Validity: Patients who received specialty palliative care were more likely to have documentation of their preferences for or against receiving life-sustaining treatments (91% vs 59%, p greater than 0.001).

Identification of Meaningful Differences in Performance

Data/Sample. Hospice: The total patient sample size was 126. Fourteen hospices, located in seven different states, representing both free-standing and hospital based providers, were recruited to participate. Each hospice was asked to contribute data from nine patient records to the study. Nine hospices were asked to collect data on their most recent nine discharges; five hospices were asked to collect data on their most recent nine admissions.

A common structured data collection tool was developed for use by all hospices, regardless of whether the patient record was an admission or discharge record. Instructions embedded in the tool indicated the data items appropriate to each type of record. Hospices were instructed not to institute new data collection procedures for the data collection pilot. If a data item could not be found, they were told to mark the item as "unable to determine."

A data dictionary containing item-specific instructions and notes related to the patient data collection tool was distributed to each hospice center. Technical assistance was provided by email and phone to staff during the data collection period. Questions, and responses, that arose during data collection were immediately distributed to all hospices participating in the data pilot.

Palliative Care: The total patient sample size was 562. Chart abstractions were completed for 102 consecutive seriously ill patients with specialty palliative care consultation, and a random sample of 460 seriously ill patients without specialty palliative care admitted to an acute care hospital for at least 1 day to four inpatient services with high proportions of seriously ill patients. Records eligible for sampling included all patients admitted to medical and surgical intensive care, medically complex patients aged 65 and older admitted to a geriatric evaluation unit, and medical oncology patients with Stage IV carcinoma. Because palliative care domains become even more relevant closer to death, patients dying in hospital were oversampled to ensure a final ratio of 1 decedent to 1 live discharge. Consistent with oversampling of decedent records, 55% of these patients died in hospital. The age of the patients ranged from 16 to 99 years, with the mean age 61. Patients were predominantly Caucasian (65%), with smaller subgroups who were African American (24%) and Hispanic/Latino (4%). The most common life-limiting diagnoses were

infections (37%), cancer (34%), pulmonary (29%), and neurologic diseases (21%).

Analytic Method. Construct validity was tested by comparing the PEACE quality measures for patients seen by specialty interdisciplinary palliative care consultants to those not receiving specialty palliative care services. Percentage of patients with and without specialty palliative care for whom the quality measure was met was compared for difference using the chi-square statistic.

Results. Hospice sample: 81.5% of patients had documentation of treatment preferences; 3% of reviewed records had no information.

Palliative care sample: Seriously ill hospitalized patients who received specialty palliative care were more likely to have documentation of their treatment preferences compared to patients without specialty palliative care (91% vs 59%, $p > 0.001$).

Evidence for Extent of Measure Testing

University of North Carolina - Chapel Hill. National Quality Forum (NQF) measure submission and evaluation worksheet 5.0: Hospice and palliative care - treatment preferences. 16 p.

State of Use of the Measure

State of Use

Current routine use

Current Use

not defined yet

Application of the Measure in its Current Use

Measurement Setting

Hospices

Hospital Inpatient

Professionals Involved in Delivery of Health Services

not defined yet

Least Aggregated Level of Services Delivery Addressed

Single Health Care Delivery or Public Health Organizations

Statement of Acceptable Minimum Sample Size

Unspecified

Target Population Age

Adult & elderly

Target Population Gender

Either male or female

National Strategy for Quality Improvement in Health Care

National Quality Strategy Aim

Better Care

National Quality Strategy Priority

Person- and Family-centered Care

Institute of Medicine (IOM) National Health Care Quality Report Categories

IOM Care Need

End of Life Care

Living with Illness

IOM Domain

Patient-centeredness

Data Collection for the Measure

Case Finding Period

Unspecified

Denominator Sampling Frame

Patients associated with provider

Denominator (Index) Event or Characteristic

Clinical Condition

Institutionalization

Therapeutic Intervention

Denominator Time Window

not defined yet

Denominator Inclusions/Exclusions

Inclusions

Seriously ill patients enrolled in hospice OR receiving specialty palliative care in an acute hospital setting

Note: This quality measure is intended for patients with serious illness who are enrolled in hospice care OR receive specialty palliative care in an acute hospital setting. Conditions may include, but are not limited to: cancer, heart disease, pulmonary disease, dementia and other progressive neurodegenerative diseases, stroke, HIV/AIDS, and advanced renal or hepatic failure.

Exclusions

Patients with length of stay less than 1 day in hospice or palliative care

Note: Calculation of length of stay: discharge date is identical to date of initial encounter

Exclusions/Exceptions

not defined yet

Numerator Inclusions/Exclusions

Inclusions

Patients whose medical record includes documentation of life sustaining preferences

Note: Documentation of life-sustaining treatment preferences should reflect patient self-report; if not available due to patient loss of decisional capacity, discussion with surrogate decision-maker and/or review of advance directive documents are acceptable. The numerator condition is based on the process of eliciting and recording preferences, whether the preference statement is for or against the use of various life-sustaining treatments such as resuscitation, ventilator support, dialysis, or use of intensive care or hospital admission. This item is meant to capture evidence of discussion and communication. Therefore, brief statements about an order written about life sustaining treatment, such as "Full Code" or "Do not resuscitate/Do not intubate (DNR/DNI)" do not count in the numerator. Documentation using the Physician Orders for Life-sustaining Treatment (POLST) paradigm with evidence of patient or surrogate involvement, such as co-signature or description of discussion, is adequate evidence and can be counted in this numerator.

Exclusions

Unspecified

Numerator Search Strategy

Institutionalization

Data Source

Electronic health/medical record

Type of Health State

Does not apply to this measure

Instruments Used and/or Associated with the Measure

Patient Data Collection Tool for Recommended Quality Measures

Computation of the Measure

Measure Specifies Disaggregation

Does not apply to this measure

Scoring

Rate/Proportion

Interpretation of Score

Desired value is a higher score

Allowance for Patient or Population Factors

not defined yet

Standard of Comparison

not defined yet

Identifying Information

Original Title

Hospice and palliative care -- treatment preferences.

Measure Collection Name

Palliative Care and End-of-Life Care

Submitter

University of North Carolina at Chapel Hill - Academic Institution

Developer

Carolinas Center for Medical Excellence - Nonprofit Organization

University of North Carolina at Chapel Hill - Academic Institution

Funding Source(s)

Centers for Medicare & Medicaid Services

Composition of the Group that Developed the Measure

The Carolinas Center for Medical Excellence (CCME) PEACE Project Technical Expert Panel (TEP)

The PEACE project team convened a 14-member TEP of nationally recognized experts with extensive experience in the following areas: medical or nursing expertise in hospice and palliative care, methods and instrumentation, and quality improvement. Using criteria provided by the CCME study team, TEP members rated each potential quality measure on four criteria: importance, scientific soundness, feasibility and usability.

Mary Ersek, PhD, RN, Research Associate Professor, Swedish Medical Center - Pain Research Department, Seattle, WA

Betty R. Ferrell, PhD, FAAN, Research Scientist, City of Hope National Medical Center, Duarte, CA

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Lin Simon, Analyst, National Hospice and Palliative Care Organization, Washington, DC

Karen Pace, NAHC

Financial Disclosures/Other Potential Conflicts of Interest

Unspecified

Endorser

National Quality Forum - None

NQF Number

not defined yet

Date of Endorsement

2016 Oct 26

Adaptation

This measure was not adapted from another source.

Date of Most Current Version in NQMC

2016 Dec

Measure Maintenance

3 years or as requested

Date of Next Anticipated Revision

Unspecified

Measure Status

This is the current release of the measure.

This measure updates the following previous versions:

The Carolinas Center for Medical Excellence (CCME). Specifications for recommended quality measures. Cary (NC): The Carolinas Center for Medical Excellence (CCME); 8 p.

University of North Carolina – Chapel Hill. National Quality Forum (NQF) measure submission and evaluation worksheet 5.0: Hospice and palliative care – treatment preferences. 16 p.

Measure Availability

Source available from the [University of North Carolina \(UNC\) School of Medicine Web site](#)

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Companion Documents

The following are available:

Assessment instruments for end of life care, by domain. Cary (NC): The Carolinas Center for Medical Excellence (CCME); 7 p. This document is available from the [University of North Carolina \(UNC\) School of Medicine Web site](#) .

Organizational readiness screen. Cary (NC): The Carolinas Center for Medical Excellence (CCME); 4 p. This document is available from the [UNC School of Medicine Web site](#) .

Patient data collection tool for recommended quality measures. Cary (NC): The Carolinas Center for Medical Excellence (CCME); 7 p. This document is available from the [UNC School of Medicine Web site](#) .

"Read this first": getting started with PEACE quality measures. Cary (NC): The Carolinas Center for Medical Excellence (CCME); 3 p. This document is available from the [UNC School of Medicine Web site](#) .

Recommended quality measures and data collection, by domain. Cary (NC): The Carolinas Center for

Medical Excellence (CCME); 3 p. This document is available from the [UNC School of Medicine Web site](#) .

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NQMC Status

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This NQMC summary was updated by ECRI Institute on February 7, 2017. The information was not verified by the measure developer.

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Production

Source(s)

National Quality Forum (NQF). Palliative and end-of-life care 2015-2016: technical report. Washington (DC): National Quality Forum (NQF); 2016 Dec 23. 209 p.

The Carolinas Center for Medical Excellence (CCME). Specifications for recommended quality measures. Cary (NC): The Carolinas Center for Medical Excellence (CCME); 8 p.

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